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HOW GOVERNMENTS COULD BEST ENGAGE COMMUNITY ORGANIZATIONS TO CO-DESIGN COVID-19 PANDEMIC POLICIES FOR PERSONS WITH DISABILITIES

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SUMMARY

The COVID-19 pandemic and the policy measures adopted in response have disproportionately impacted persons with disabilities. Given the increased risk of COVID-19 and the resulting health impact for this vulnerable population, governments must engage stakeholders such as community organizations to co-design pandemic response plans. Collaboration with key stakeholders could assist in transforming services in crucial areas, such as health, where emergency policies are organized around the needs of persons with disabilities.

Unfortunately, there is inadequate data collection and insufficient emergency preparedness planning and responses for persons with disabilities. This knowledge gap means consideration of health and social policy implications specific to the needs and experiences of persons with disabilities is lacking. This research study aimed to evaluate strategies through which decision-makers could engage stakeholders, such as community organizations, to co-design disability-inclusive policy responses during the COVID-19 outbreak in Alberta.

Through interviews, the study focused on understanding the level of engagement, barriers to community organizations' engagement and participatory policy aspects best suited for co-design. Key findings from the research highlighted the participants' viewpoints on barriers, facilitators, preferences and other critical approaches through which decision-makers

engage with community organizations. Results highlighted that top-down and tokenistic consultation approaches limit community organizations' engagement in designing pandemic planning and response. Inaccessible ways of consultation and navigation barriers exacerbate obstacles to stakeholder engagement. Stakeholder engagement in data surveillance efforts was unclear, and the impact assessment process needs strengthening. The study results also showed that having COVID-19 disability advisory groups at the federal and provincial levels are a robust mechanism to connect communities with the government. However, the process of influencing government decision-making and policy actions needs to be openly communicated to civil society.

Solutions are achievable. Political commitment, long-term investments and an accessible engagement environment would significantly improve stakeholder engagement. Governments must transition from traditional consultative methods to sustainable engagement practices while sharing how public policies reflect communities' input. Financial investments must create an accessible consultation environment for designing participatory pandemic policies that reflect the priorities of persons with disabilities.

Some key recommendations emerging from our analysis include:

- Invest financially to create an accessible consultation environment for codesigning policies.
- Consult stakeholders to develop new regulations or adjust existing ones to create inclusive pandemic response plans.
- Inform how pandemic response plans include and address community inputs and concerns in a transparent manner.
- Professionally contract stakeholders to co-design and communicate pandemic information.
- Engage with multiple stakeholders to evaluate the impact of pandemic response plans.

I. INTRODUCTION AND BACKGROUND

Persons with disabilities, aged 15 and above, are 22 per cent of Canadians who experience significant health disparities relative to the general population (Canada 2021). These disparities are accentuated by the COVID-191 pandemic (WHO 2020a) and negatively impact access to emergency information, programs and services for persons with disabilities (WHO 2020a). Persons with disabilities require special consideration during the pandemic response because of barriers to societal participation and the disproportionate impact of the COVID-19 outbreak (Kuper et al. 2020). They have experienced systematic discrimination and adverse outcomes due to ableist pandemic responses (Felt et al. 2021). Ableism refers to societal attitudes and discriminatory practices that devalue the potential and participation of persons with disabilities (Ontario Human Rights Commission 2016). For example, during the COVID-19 pandemic in the U.S., governments in various states developed medical triaging protocols that selected patients based on their quality of life. This excluded persons with disabilities from intensive care triage guidelines and the distribution of scarce resources (British Medical Journal 2020). In addition, commonly used risk communication approaches during emergencies skew toward audio-visual messages, often without closed captioning or sign language interpreters, leading to confusion and anxiety (Stough and Kang 2015).

Persons with disabilities are also disadvantaged by COVID-19's socioeconomic impacts, disproportionately experiencing lower income, employment, educational attainment and poor health outcomes (Lancet 2020b). To support persons with disabilities during the pandemic, Canada implemented a COVID-19 economic response plan. It included the Disability Tax Credit, a one-time, tax-free credit payment of \$600, along with an additional \$750 in financial benefits for students with disabilities under the Canada Emergency Student Benefit (CERB). Due to the economic tools' narrow inclusion criteria based on eligibility for the disability tax credit, which included working-age Canadians with severe disabilities, these policy responses excluded many persons with disabilities, particularly those with autism spectrum disorder (Abel and Lai 2020; Dunn and Zwicker 2018).

The COVID-19 pandemic has profoundly impacted the physical and mental health outcomes and overall quality of life of persons with disabilities and their caregivers (UNICEF 2020; WHO 2020b). Service disruption has resulted in many mental health issues, including increased isolation, higher anxiety levels, behaviour changes and sleep disturbances relative to the pre-pandemic period (Lancet 2020b). Persons with developmental delays, for example, have been reported to be five times more likely to be infected and four times more likely to die from COVID-19 than others (Hakim 2020; McQuigge 2020).

In recognition of Canada's domestic and international human rights obligations it is essential to address and mitigate the risk of infection and the resulting health issues

COVID-19 is an infectious disease caused by a newly discovered coronavirus, which was first identified in Wuhan, China, in December 2019. On March 11, 2020, the World Health Organization (WHO) declared it a pandemic.

pandemics pose. The Sendai Framework² recognizes the unique needs of persons with disabilities and recommends stakeholders such as community organizations be included in designing inclusive emergency preparedness plans (Stough and Kang 2015). The framework's guiding principles particularly recognize community organizations as experts in designing critical pandemic aspects, as they are the first point of contact for persons with disabilities and their families (United Nations Office for Disaster Risk Reduction 2015). Unfortunately, there is often a lack of a structured mechanism to understand if the perspectives of community organizations have been integrated into decision-making processes (Phillips and Orsini 2002).

CURRENT COVID-19 POLICY APPROACHES

Throughout the pandemic, governments and organizations have used several approaches in Canada to flatten the curve and reduce the spread of COVID-19. The policy approaches can be categorized as public announcements, social distancing and self-isolation policies, non-essential workplace closure and health facility restrictions such as triage policies and medical visitation policies (McCoy et al. 2020). Many people with disabilities and their families cannot always adhere to the guidelines. For example, youth with disabilities can experience intensive care hospital settings without family support for communication and mediation (Pulrang 2020). With the onset of subsequent COVID-19 waves, governments at various levels introduced public health measures such as mandatory mask bylaws in indoor spaces to reduce COVID-19 transmission (Lancet 2020b). Following mask bylaws is particularly hard for persons with sensory issues, due to medical barriers (Kohek et al. 2020).

PARTICIPATORY POLICY CO-DESIGN

Aligning the pandemic response policies in recognition of the *Accessible Canada Act*³ and Canada's commitment to Convention on the Rights of Persons with Disabilities (CRPD)⁴ is critical to improving the health outcomes of persons with disabilities. A disability-inclusive pandemic response requires that governments engage representative organizations, assess their needs to match policy and community-based solutions and implement approaches to enhance the organizations' capacity to cope with the local and global health outbreaks. After the 2009 H1N1 influenza pandemic in Ontario, a participatory engagement approach was implemented to meet isolated sub-Arctic First Nations communities' evolving needs and improve health outcomes for future emergencies. First Nations communities and local and provincial health agencies collaborated to successfully develop community-informed and culturally appropriate pandemic response plans (Charania and Tsuji 2012).

The Sendai Framework for Disaster Risk Reduction (SFDRR) was adopted in 2015 at the World Conference on Disaster Risk. The framework integrates underpinnings of accessibility and inclusion to conceptualize its preamble and guiding principles for vulnerable population groups, including persons with disabilities.

The Accessible Canada Act came into force on July 11, 2019. It is an act to ensure a barrier-free Canada through the proactive identification, removal and prevention of barriers to accessibility wherever Canadians interact with areas under federal jurisdiction.

The United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD) in 2006. It is an international human rights treaty intended to protect the rights and dignity of persons with disabilities.

Participatory policy design approaches, also known as co-design, can reduce negative impacts and the immediate threat posed by pandemics and build resilience for future pandemics (Campbell et al. 2009). Co-design means engaging stakeholders to find solutions to complex societal issues. In the public policy arena, co-design marks a significant movement away from developing policies and implementing programs for people to designing them with people, leading to a citizen-centric policy framework (Brookfield Institute 2018; Phillips and Orsini 2002).

THE NEED TO CO-DESIGN PANDEMIC RESPONSE PLANS WITH STAKEHOLDERS

Co-designing pandemic planning and responses in consultation with stakeholders, such as community organizations, can create inclusive policy responses. Often, the pandemic response involves a top-down consultative approach. Usually, government officials, public health agencies and legal experts develop pandemic response plans and inform communities about them, instead of seeking input from communities and integrating the information into the response planning and decision-making from the beginning (British Medical Journal 2020; Arya et al. 2009).

Another benefit of engaging community organizations in developing pandemic responses is recognizing the intersectionality of socioeconomic factors (Dimka and Mamelund 2020). Research has shown that the prevalence of disability is highest among those living in poverty, and together these aspects limit access to services and programs (Campbell et al. 2009). In 2007, the Quebec government announced a new public policy regulating social housing funding for persons with mental health issues. It resulted from innovative participatory practices previously implemented by community organizations and public-sector officials who represented health and housing issues for low-income individuals (Vaillancourt 2009).

Finally, co-designing pandemic response plans ensures that lessons from a health emergency could be applied and adapted to design policies for persons with disabilities in the face of future crises (Campbell et al. 2009), while making them less susceptible to COVID-19 morbidity and mortality issues (Lunsky et al. 2018). In Canada, for example, the National Advisory Committee on SARS and Public Health, established by the federal government, suggested creating partnerships with the voluntary sector to reduce health risks to at-risk population groups (Canada 2003).

In light of the above, we evaluated strategies through which decision-makers could engage stakeholders such as community organizations to co-design disability-inclusive policy responses during the COVID-19 outbreak in Alberta.

II. RESEARCH METHODOLOGY

The University of Calgary Conjoint Faculties Research Ethics Board approved this research (Ethics ID: REB19-2158). The primary researcher conducted qualitative, semi-structured interviews. Semi-structured elements guided the interviewer to ask questions that addressed the research objectives and provided comprehensive information. The open-ended nature of the questions facilitated a flexible coverage of

the key thematic areas and further probing of critical information. Simultaneously, the questions enabled participants to articulate their viewpoints in a dialogue. Participants were asked questions from an interview guide with four themes, including engagement strategies with stakeholders during the COVID-19 pandemic, communication mechanisms for disseminating pandemic information, monitoring and evaluation of the pandemic plan and a social policy hub model for co-designing evidence-based policies. At the end of the interview, interviewees had an opportunity to address co-design challenges they felt were not discussed.

PARTICIPANTS' SELECTION

We recruited 12 participants from relevant government ministries in Alberta along with federal and Albertan disability advisory groups that comprised of persons with lived experiences, self-advocates, representatives from community organizations and academicians. Participant recruitment was done using purposeful and snowball sampling methods. Participants were contacted by email and given a consent form that described the purpose of the research and privacy and confidentiality approaches. Participation was entirely voluntary, and participants were not paid. The primary researcher ensured that interview times and meeting spaces accommodated participants' needs. We collected the data between June 2020 and July 2020. Purposeful sampling helped target the decision-makers working in a leadership capacity with the Alberta government, subject matter experts and advisory board members for persons with disabilities across all government levels who have experience in policy-making and program management for vulnerable communities. The recruited decision-makers work with community organizations to facilitate pandemic programs and services that benefit persons with disabilities and their families.

The following table illustrates the demographic information of the participants:

Table 1: Demographic Information of Interview Participants

Research Sample Size (n)	Participants' Levels of Government	Geography	Participants with Lived Experience	Gender
	Provincial Government	Alberta	No	Total Female Respondents: 6
	Municipal Government	Alberta	Yes	Total Male Respondents: 6
	Provincial Disability Advisory Group	Alberta	Yes	Total Female Respondents with Lived Experience: 3
	Federal Disability Advisory Group	Canada	Yes	Total Male Respondents with Lived Experience: 2

INTERVIEW ANALYSIS

The average length of the interviews was 40 minutes, and interviews were conducted through video conferencing due to COVID-19 physical distancing norms. Interviews were recorded and documented using a descriptive transcription method, meaning all conversations were transcribed as a detailed account of the audio file. The transcribed documents were imported into NVivo version 12.0 software, an application used to organize qualitative data (NVivo 2018). Data analysis was guided by interpretive

description, using an inductive thematic approach. The analysis process included reading interview responses, developing main policy themes, creating sub-categories within the thematic areas, systematic collation and coding data into thematic areas and sub-themes. Codes were categorized, and data were collected until new data did not significantly contribute to existing themes.

The primary researcher incorporated feedback from the principal investigator and co-investigators throughout the process of designing the study. Rigour was established by evaluating and validating codes, themes and sub-themes with the principal investigator and co-investigators, and returning to the published literature to look for places where the data supported or added to what was previously published. From there, core constructs and contributing concepts were identified. The process facilitated understanding best practices and barriers and gaps in engaging stakeholders in codesigning pandemic policies.

III. RESULTS

The discussion's central theme was engagement with community organizations to codesign pandemic response plans. Participants shared perspectives and experiences on engagement and mentioned a range of community organizations, including nonprofit organizations, self-advocates, coalitions with lived experiences and family-led organizations.

Thematic analysis of the interviews generated the following policy themes:

- 1. Barriers to Stakeholder Engagement
- 2. Overcoming Barriers to Engagement (Facilitators)
- 3. Monitoring and Evaluation

The following figure represents the research interviews' key policy themes and subthemes and describes participants' viewpoints, suggestions and nuanced information gathered on thematic areas.

Figure 1: Key Policy Themes and Sub-themes of the Research Study



BARRIERS TO STAKEHOLDER ENGAGEMENT

Many participants from the provincial government and federal advisory group stated that inaccessible consultation and its cost, non-inclusive policy responses, distribution of power, tokenistic engagement approaches and differences of priorities between governments and community organizations prevent stakeholders from achieving optimal engagement.

Consultation Accessibility and Cost

Advisory group participants indicated accessibility and navigation as the most common barrier that prevents full engagement of a wide range of community organizations in co-designing policies. Participants mentioned that traditional engagement approaches such as community consultation or surveys are devoid of inclusive elements such as accessible buildings, access to special transport for medically fragile individuals and inclusion of consultation tools in plain language. Some participants pointed out that many persons with developmental disabilities from low-income households depend on income support programs in Alberta, such as AISH,⁵ and have inadequate access to technology and transportation to participate in virtual and physical engagement sessions. A participant mentioned that "there are barriers to engagement, particularly for people on programs like AISH. The barriers are about transportation to get to the venue and accessibility for internet connection."

Assured Income for the Severely Handicapped (AISH) is a financial and health benefit for eligible Albertans with a permanent medical condition that prevents them from full employment.

Furthermore, the provincial and municipal governments' participants said that creating an inclusive engagement environment is intensive in terms of money and time, particularly during the Alberta government's current budget constraints. Federal advisory group participants said that even though the *Accessible Canada Act*⁶ consultation was an expensive engagement process, it emphasized the values of respect for inputs and acknowledgment of the barriers at-risk communities face.

Non-inclusive Policy Responses

Advisory group participants expressed their concerns that stakeholder engagement and pandemic response policies lack political will and a disability lens. A participant shared that "governments could have multiple advisory bodies that may look good on paper, but sometimes these approaches are tokenistic in nature. Well-rounded disability policymaking with or without pandemics depends on the government's willingness to include the experts' recommendations." The participants also shared that the response strategies are often made by people with a limited understanding of day-to-day situations experienced by persons with disabilities, which further exacerbated challenges. For example, initially, there was an absence of sign language interpreters and closed captioning in the daily briefings carried out by Alberta's chief medical officer.

Power Imbalance

Power distribution was another major impediment to an optimal co-design process. Many advisory group participants believed that dominant voices, particularly from prominent organizations and self-advocates, tend to frequent the engagement sessions. These organizations have more robust networks with the government to raise their voices as opposed to smaller organizations or those in rural areas with limited capacity and outreach. A participant shared that "I believe that larger organizations have louder voices because they feel more confident. Persons with disabilities can be afraid of saying things." Some participants said that many times, the same organizations are invited to the decision-making table. Another viewpoint was that the fear of participation and repercussions prevents stakeholders from providing opinions in the government's decision-making process.

Methods of Engagement

The federal and provincial advisory group participants said that tokenistic ways of engagement were a significant barrier. They said that although the government actively solicits stakeholder feedback through the consultation process, there is a gap in communicating whether the inputs have been accepted and how they shape a policy or legislative guidelines. A participant from the provincial government suggested that a balanced approach to co-design is to communicate with stakeholders how much information the government can share and why it cannot engage communities on every matter. The participant mentioned that "The problem we have right now in Alberta and

The Accessible Canada Act 2019 builds on Canadian human rights benefiting all Canadians, especially persons with disabilities, by removing and preventing barriers to accessibility.

nationally as well is that there are some significant fiscal constraints right now. So I think co-designing has to recognize that."

Divergent Priorities

Some advisory group participants noted issues with different priorities between the government and the community. They stated that the government's priorities reflect its organizational culture, program targets and department budget; the community's priorities are often fragmented in a silo-based approach. Participants stated that many disability groups have emerged over time, and they all want to set policy agendas. A lack of collective approach among pan-disability groups regarding engagement on policy issues was a central message. A participant shared that "it is better to go as a collective with the key priority areas in the future. I think that community organizations can't selfishly think of the needs of people they operate with."

OVERCOMING BARRIERS TO ENGAGEMENT (FACILITATORS)

In the government's pandemic response plan, overcoming stakeholder engagement barriers included creating an accessible engagement environment and innovative engagement mechanisms. Participants highlighted several promising approaches to address the barriers.

Accessible Consultation Approaches

Participants spoke of the need for physically and logistically accessible consultation to overcome engagement barriers for participatory policy-making. Several participants recommended accessible venues and restructuring of dialogues. They mentioned improving the accessibility of venues, including washrooms and presence of ramps, sign language interpreters, closed captioning for presentations and use of plain language for disseminating information. Participants also suggested arranging transportation for medically fragile or economically disadvantaged stakeholders. A participant said that "seeking input from the stakeholders on how to design consultation meetings inclusively would be helpful for engagement."

Participants recommended innovative consultation approaches, such as setting up advisory councils and discussing less technical questions, with more emphasis on ideas and stories to create a rich input database. A participant shared that "a local advisory group has previously used focused group sessions for persons with disability program (PDD)7 review across Alberta with different stakeholders, including caregivers, families, self-advocates, all consulted in different rooms."

Simple Communication

Strikingly, every participant said that pandemic information in a simple and easy-to-understand manner is the most preferred co-design aspect, since community

Persons with Developmental Disabilities (PDD) helps adults with developmental disabilities in Alberta to get services to live as independently as possible in their communities.

organizations and families are well-equipped to communicate with persons with disabilities. A poorly worded policy can have a significant impact on a person's quality of life. A participant mentioned that "protocols and program information is highly technical and confusing for persons with disabilities to understand and interpret." In terms of communicating COVID-19 information, including facts, risks and testing criteria, nearly all participants mentioned that provincial governments had done an excellent job explaining these aspects in simple terms. However, the lack of plain language communication in emergencies was an issue. One participant mentioned that the province has yet to learn from the Fort McMurray fire emergency⁸ to communicate in simple language.

Stakeholder Engagement and Capacity Building

Most participants mentioned the significance of engaging stakeholders such as community organizations in the pandemic communication plan and protocols while building their capacity to develop the strategies. Participants suggested that community organizations could play an educational role in disseminating pandemic protocols and interventions inclusively, understanding the community's concerns about the response plan and perceived gaps in relaunch strategies. In addition, community organizations could also be involved in reviewing pandemic plans and helping the government tweak the plans. A participant noted that "governments could play a significant role in contracting disability groups to design and implement pandemic messaging, acknowledging their expertise, and helping them with their capacity."

'Policy Hub' as a Preferred Approach

Almost every participant said that organizations need to be more cohesive and respectful when representing the issues that the communities face. Many participants suggested that finding common priorities across different disability groups is optimal, particularly during emergencies. Coalitions in the form of a task force, collectives or a social policy hub were suggested to solicit governments while proposing solutions to the issues instead of echoing them. Every participant viewed the development of a hub as a valuable proposition that could foster the testing of ideas, and proving and disproving assumptions with data and research. Participants believed that academia could consciously bring an independent scientific lens to complement the municipal and provincial governments' strategic priorities to engage stakeholders in policy development. One participant exemplified the point by stating that "this approach would be helpful as the COVID-19 pandemic has tested different ministries' capacity to work together on common issues."

MONITORING AND EVALUATION

The participants stressed the need to monitor and evaluate pandemic responses. However, some people's opinions differed regarding assessment mechanisms.

In May 2016, Fort McMurray, Alberta experienced a massive wildfire that destroyed around 2,400 homes and businesses.

Assessment Mechanisms

Participants from the provincial government said that using an external impact assessment agency to evaluate issues that vulnerable clients face concerning COVID-19 guidelines was a good approach. However, the federal and provincial advisory groups' participants thought that direct engagement with organizations that work with persons with disabilities is critical. Others noted that evaluations haven't yet been possible, stating "the pandemic response is evolving as the city transitions from one phase to another. The response plan has not been evaluated yet in a robust manner."

Key Performance Indicators (KPI)

Most participants mentioned that the pandemic response evaluation does not include performance indicators, primarily through feedback loops. They said that governments could have well-defined KPIs to track significant health-related issues for persons with disabilities. A participant from the federal advisory group suggested "tracking information, such as mortality rates at unlicensed facilities, and how it is different from licensed facilities." Some participants suggested that evaluation methods such as rapid surveys, anecdotal documentation and publications generate evidence for future pandemics. They stressed the need to bring governments, community organizations and academics together to collect data and influence policy-making.

IV. DISCUSSION

BARRIERS TO STAKEHOLDER ENGAGEMENT

Core barriers to co-designing pandemic response plans that emerged from this research included consultation accessibility and cost, tokenistic engagement methods, power imbalances, divergent priorities of decision-makers and stakeholders and non-inclusive pandemic response policies.

Consultation Accessibility and Cost

Many participants shared their concerns about the inaccessible built environments and navigation of engagement approaches limiting co-designing policies and programs. The participants from government agencies also shared that the co-design process needs to recognize the fiscal constraints governments face.

The Government Digital Services (GDS), a unit of the United Kingdom's Cabinet Office, is an example of accessible consultation approaches, including the use of plain English for documentation, sign language translators and accessible technologies for consultation sessions, followed by an audit on accessibility components to create inclusive engagement opportunities (The United Kingdom 2018). Regarding fiscal constraints, previous studies have demonstrated that bringing systematic changes to funding allocation at the beginning of program and policy design facilitates a meaningful and respectful consultation (Phillips and Orsini 2012).

Methods of Engagement and Power Imbalance

Research findings indicated that tokenistic consultation methods affect civil society's trust in community engagement (Sheedy 2008). Factors such as the government's lack of communication on how consultation inputs are integrated into policy responses and how pandemic responses specifically include the needs of persons with disabilities and the percolation of similar voices in the consultation process undermine the real purpose of engagement (Phillips and Orsini 2002). The concerns also resonated with Canada's independently led SARS commission, which recommended collaboration and political disposition to overcome systematic issues during health outbreaks (Canada 2003). Well-rounded disability policy-making is correlated with the government's willingness to include recommendation(s) provided by the stakeholders while informing how the input is reflected in the response policies. Research findings revealed that COVID-19 visitation policies lacked a horizontal consultation and missed the inclusion of the needs of persons with disabilities and their families.

Divergent Priorities

This research found that disability groups lack cohesiveness and often approach the government with different priorities specific to their organizations. Participants recommended that stakeholders approach governments respectfully to find collective priorities and solutions that represent persons with disabilities to get on the policy agenda. A co-design pilot implemented in Australia's primary health-care field found that principles such as agenda setting, constructive criticism and outcomebased leadership, when established in the early stages, led to enhanced trust and collaboration among partners (Greenhalgh et al. 2016).

Non-inclusive Policy Responses

Many participants raised the concern that decision-makers often consult public health agencies but not community organizations that represent persons with disabilities during health emergencies, which results in a broader level of pandemic response protocols and guidelines that exclude the priorities of at-risk communities. For example, many cities in Canada have made wearing masks compulsory in public spaces. Fear of being confronted, assaulted and discriminated against by not wearing masks due to medical barriers increases their anxieties, prevents safe public participation and can push persons with disabilities into further isolation (Kohek et al. 2020). A survey report by a human rights-based global monitoring initiative, the COVID-19 Disability Rights Monitor, found that many countries, including Canada, have overwhelmingly failed to take sufficient measures to protect the rights of persons with disabilities in their responses to the pandemic (Disability Rights Monitoring 2020). Collaboration with representative organizations could help develop inclusive pandemic response plans that address unforeseen barriers faced by persons with disabilities.

OVERCOMING BARRIERS TO ENGAGEMENT (FACILITATORS)

Accessible Consultation Approaches

The research findings revealed that accessible spaces, sensitive communication mechanisms and accessible transportation to the consultation venue, accelerate inclusive engagement. A participant said that "Accessible Canada Act consultation sessions included features essential for a well-rounded co-design process." Research has found that working with community organizations to design consultation sessions that emphasize overcoming economic, socio-cultural and spatial barriers and facilitating special accommodations is key to inclusive engagement (Sheedy 2008). In 2019, the City of Ottawa addressed transportation barriers, provided accessible wheelchairs, included communication considerations and availed personal support workers to provide barrier-free consultation opportunities for stakeholders to prepare the city's Municipal Accessibility Plan (Ottawa 2019). Considering the Accessible Canada Act, it is essential to establish policies that remove barriers (Canada 2020).

The role of the governmental advisory groups was highlighted as a powerful mechanism representing the interests of persons with disabilities during this time of public health crisis. Findings suggest that advisory committees are a critical bridge in policy discussions between the community and government (Phillips and Orsini 2002).

Simple Communication

The research found that communication of pandemic information in simple and understandable language is the most preferred aspect for co-design with community organizations. Participants from advisory groups were worried about the consequences of poorly communicated policies in the lives of vulnerable individuals and strongly preferred to partner with stakeholders for developing tailor-made communication materials from the early days of a pandemic until relaunch phases. Research studies have shown that during emergencies such as Hurricane Katrina, deficiency of easy-to-understand information and inadequate communication strategies further deteriorated the mental health of persons with disabilities (National Council on Disability 2005; Gillespie et al. 2016).

Stakeholder Engagement and Capacity Building

A significant step in planning for pandemic preparedness is the accessibility of information during and after the pandemic (Campbell et al. 2009). Investing in pandisability communication mechanisms at the early stages of the pandemic and contracting disability agencies to create inclusive messages while building their capacity could mitigate the risks. The organizations have the expertise and outreach to support the government's emergency preparedness planning efforts for the clients they serve and should be included in designing communication plans. For instance, during the Ebola outbreak in West Africa, humanitarian organizations and local government staff collaborated with community-based organizations to create adapted communication strategies for vulnerable groups (Gillespie et al. 2016). The study found that building partnerships with the community organizations, training staff on

agreed-upon objectives and implementing and delivering key messages strengthened understanding of vulnerable communities' emergencies and resilience.

'Policy Hub' as a Preferred Approach

The social policy hub gained traction as an innovative participatory policy-making mechanism. Many participants emphasized that participatory research done by a competent and autonomous body would help the government relate policies to the lived experiences of persons with disabilities and complement Alberta's priorities, such as getting Albertans back to work. The advisory groups said that initial engagement sessions could be implemented with different participants to reduce the fear of participation and increase space for solutions of complex policy issues. The European policy lab has previously designed one of the promising engagement approaches, which incorporated scientific methods to help policy-makers attain their goals on the most pressing issues. The lab organized sustainable development workshops that systematically engaged various stakeholders individually and collectively (Kimbell and Alujevic 2020).

MONITORING AND EVALUATION

One of the gaps that this research discovered was the lack of well-defined key performance indicators. The participants mentioned that evidence-based learnings from the previous pandemics in Alberta are not fully integrated into the COVID-19 response. Researchers have highlighted that the impact of previous health emergencies, such as SARS, on vulnerable groups had not been systematically captured and integrated into the face of future epidemics (Hak et al. 2004). Lessons disseminated jointly by UNICEF and West Africa's Ministry of Health after the Ebola outbreak found that local community engagement in developing a monitoring and evaluation framework is critical to pandemic planning (Gillespie 2016).

The Sendai Framework outlines the state's core responsibility to collaborate with community organizations to assess the effectiveness of emergency response plans. Establishing a strategic partnership with local community representatives in data collection and performance monitoring at the early stages of a pandemic could improve support services' design and promote the equitable distribution of costs and benefits of response monitoring.

V. LIMITATIONS

The semi-structured interview enabled participants to articulate their perceptions and experiences in a dialogue (DeJonckheere and Vaughn 2019). The research participants had experience in public policy-making and program development. They sometimes brought in their aversions and affiliations to the responses, a universal human feature. More extensive consultation is needed in designing specific policy tools. In addition, the sample size concerning government-based decision-makers could have extended beyond the senior leadership team. Mid-level staff could have provided richer input on key implementation issues and effective methods to engage community organizations

in co-designing pandemic response plans. Finally, the research findings are less representative for other vulnerable population groups, as issues faced by persons with disabilities during health emergencies might not be relatable to the other groups with the same degree of certainty.

VI. FUTURE RESEARCH DIRECTIONS

This study shows the importance of co-designing policies and interventions for health emergencies. Future work should engage persons with disabilities and their families around co-design priorities. A jurisdiction-level search across Canada could help identify promising practices for engaging families of persons with disabilities in co-designing COVID-19 policy responses. Future research could also explore the role of the federal government's COVID-19 disability advisory groups to include the priorities of persons with disabilities in areas such as health, education and employment, once the pandemic has subsided.

VII. POLICY RECOMMENDATIONS

1. Invest financially to create an accessible consultation environment for codesigning policies.

Establishing an accessible consultation environment is critical to successfully engaging the community organizations to co-design inclusive policies and accessible services. Although the *Accessible Canada Act's* engagement was expensive, it was needed to interact with citizens in meaningful ways to establish a barrier-free Canada.

2. Consult stakeholders to develop new regulations or adjust existing ones to create inclusive pandemic response plans.

Consulting stakeholders in developing and enforcing pandemic response ensures that policies are inclusive and consider vulnerable groups' circumstances. Adjusting regulations based on the stakeholders' input creates an inclusive response and improves marginalized groups' health outcomes. The adjustments also help governments avoid potential litigation by the groups who are negatively affected by non-inclusive policies.

3. Inform how pandemic response plans include and address community inputs and concerns in a transparent manner.

Disability advisory groups could be instrumental in communicating how pandemic protocols address the needs of persons with disabilities. In the shorter term, Alberta's advisory group's mandate could be fine-tuned to represent unique issues faced by persons with disabilities during the COVID-19 pandemic. The group members' role and the process of influencing the policy actions that reflect the input from community organizations must be openly communicated.

4. Professionally contract stakeholders to co-design and communicate pandemic information.

Professional collaboration with community organizations will ensure that pandemic information is simple enough to comprehend by persons with disabilities and service providers, protocols are easy to abide by and information uptake is optimal. Engagement with community agencies to design and communicate the protocols, for example, in plain language, while building their capacity can bring in an equity lens that meets the unique needs of persons with disabilities. Alberta may consider the Sendai Framework's approach to partnering with stakeholders to co-design pandemic policies.

5. Engage with multiple stakeholders, including academics, to evaluate the impact of pandemic response plans.

Engaging community networks, including community organizations, caregivers and researchers in data surveillance of pandemic response plans improves service design and health outcomes of persons with disabilities. Defining a disability performance matrix at the beginning stages with multiple stakeholders is also critical to measure the pandemic's impact. Decision-makers could use the Sendai Framework to assess the pandemic's impact, document the evidence and disseminate learning.

VIII. CONCLUSION

This research study showed that it is critical to include at-risk population groups' needs in pandemic response planning. Therefore, community engagement is essential to codesign inclusive policies. We argue that overcoming barriers to engagement requires a long-term investment and accessible engagement. Communication of pandemic information in accessible formats for persons with disabilities was the most preferred area of co-design. Simultaneously, the community organizations' expertise in data surveillance must be built and leveraged upon in future pandemics. Such approaches could ensure that persons with disabilities could holistically achieve their health and development goals and reduce the disparities and inequities they face.

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